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## The intervention model for affective involvement and its effectiveness

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## CHAPTER 6

### **Summary, conclusions, and general discussion**

In this thesis, we addressed the central role of affective involvement (the mutual sharing of emotions) in social interaction and communication with persons with congenital deafblindness. Affective involvement may be crucial for well-being because it evokes positive emotions and reduces negative emotions. However, fostering affective involvement based on the tactile modality with persons with congenital deafblindness, can be challenging for communication partners responsible for creating dynamic emotional exchanges. Guidelines and support are needed for fostering affective involvement during social interaction and communication in daily practice.

The aim of the studies presented in this thesis was to develop and evaluate the effectiveness of the IMAI, a diagnostic intervention model for fostering affective involvement between persons with congenital deafblindness and their communication partners in naturalistic settings. These studies examined whether the IMAI increased dyadic affective involvement, and increased positive emotions and decreased negative emotions in persons with congenital deafblindness. In addition to an introduction (Chapter 1), the thesis includes one theoretical study (Chapter 2) and three empirical studies (chapters 3, 4, and 5). In this concluding and final Chapter (Chapter 6), we summarize and reflect upon the results of the four studies.

## **6.1 Summary of the four studies**

### **Study 1.**

This study (Chapter 2) describes the background and development of the IMAI. First, it addresses the importance of affective involvement for social awareness and promoting interpersonal relationships and the theoretical underpinnings of the model. Second, it highlights key features of fostering affective involvement during interaction and fostering affective involvement during communication. Third, the IMAI is introduced by describing its aim, intervention principles and protocol. The interventions based on the IMAI have two consecutive phases (Phase I, which focuses on fostering affective involvement during interaction, and Phase II, which fosters affective involvement during communication) and are applied by a trained coach. The coach implements the intervention using a seven-step protocol. During the first step of the protocol, the coach receives a request for coaching from the communication partners or psychologist concerning difficulties in recognizing, understanding, and regulating emotions with a person with congenital deafblindness. During the second step, the coach gathers additional information about the different functioning domains of the person with congenital deafblindness and consults the team of communication partners to formulate the target questions for coaching. During the third step, the coach uses video analysis to formulate intervention aims and target behaviors during interaction based upon four core behavior categories. During the fourth step, the coach trains the communication partners in changing their interactive behaviors according to the intervention aims.

During the fifth step, which marks the beginning of Phase II of the intervention, the coach uses recent video recordings to determine intervention aims and target behaviors during communication based upon three core behavior categories. During the sixth step, the coach trains the communication partners in changing their behavior during communication. Finally, during the seventh step, the coach evaluates the intervention with the team of communication partners and together they determine whether the intervention should be stopped or continued.

### **Study 2.**

The objective of the second study (Chapter 3) was to conduct a pilot study to empirically test the applicability of the IMAI and its effectiveness. For this purpose, the IMAI was applied to one adult participant with congenital deafblindness and his five caregivers in two different settings (daytime activities center and group home) and different interactional situations in an organization specialized in communication and auditory and/or visual disabilities. The researcher (first author) coached the caregivers during team and individual coaching to ensure the IMAI was implemented correctly.

The IMAI proved applicable and effective in both settings. It improved the participant's affective involvement and emotional behavior. In both settings, we saw an increase in affective involvement and very positive emotions as soon as the intervention began, with the clearest effects occurring in the daytime activities center. Negative emotions decreased in the daytime activities center. During follow-up, affective involvement decreased in both settings but remained above baseline level. As expected, fostering affective involvement was more complex for the caregivers during communication than during interaction: they found it more difficult to share experiences and meaning during communication. The caregivers also indicated that it was easier to share positive than negative emotions.

### **Study 3.**

The third study (Chapter 4) reports the findings of the implementation of the IMAI for four participants with congenital deafblindness (two children and two adults) and their 16 communication partners (teachers, teacher assistants, caregivers and caregiver assistants) in three different settings (school, group home and daytime activities center) and different interactional situations in the same organization as study 2. Three trained coaches applied the seven-step intervention protocol. A multiple-baseline design was used to examine the effects of the intervention.

In line with the pilot study, it proved possible to apply the IMAI in all settings. The different communication partners learned to attune to the interactive behaviors and emotions of the participants with congenital deafblindness and to share emotions and meanings. Dyadic affective involvement increased for three of the four participants and all four participants displayed an increase of very positive emotions and a decrease of

negative and very negative emotions. Also in line with the pilot study, the occurrence of affective involvement dropped during follow-up for all but one participant in one of the settings. It appeared difficult to maintain affective involvement over time, which suggests that communication partners should be coached on a more permanent basis or at least at regular intervals. During evaluation, the communication partners confirmed that it was more practical and effective to first focus on fostering affective involvement during interaction before being coached to foster affective involvement during communication.

#### **Study 4.**

The fourth and final study (Chapter 5) examined whether the IMAI could be successfully applied to persons with congenital deafblindness and an intellectual disability who receive services from organizations with expertise on intellectual and/or visual disabilities. Communicating with these people is even more difficult. They have been deprived of social interactions involving affective involvement because these organizations did not provide deafblind-specific education. If the IMAI proved to be applicable, it would increase confidence in the reliability and generalizability of our findings across persons with congenital deafblindness.

The IMAI was applied to four adult participants and their 13 communication partners (caregivers and caregivers assistants) in different interactional situations in four different organizations. Four new coaches were trained to apply the intervention protocol. Similar to the former study (study 3), a multiple-baseline design was used to examine the effects of the intervention during the different intervention conditions (baseline, Phase I and Phase II of the intervention, and follow-up). Due to time limitations, follow-up measures could only be taken for one participant and his five communication partners after 2, 4, and 6 months.

An increase of dyadic affective involvement and an increase of the participant's very positive emotions and a decrease of negative and very negative emotions was observed in all four participants. In line with the two former studies, the IMAI proved effective for different communication partners and interactional situations. Findings of the follow-up revealed that affective involvement was maintained at a high level. However, the strong downward trend during follow-up suggests that there is a serious risk that affective involvement cannot be maintained when communication partners receive no further coaching.

## **6.2 Conclusions**

The results of this thesis can be summarized in the following three main conclusions:

- (1) Interventions based on the IMAI are effective in increasing affective involvement between persons with congenital deafblindness and their communication

partners, and in increasing positive emotions and decreasing negative emotions in persons with congenital deafblindness.

- (2) Interventions based on the IMAI are effective for fostering affective involvement during interaction and communication.
- (3) Interventions based on the IMAI are widely applicable: they are effective in both children and adults, and across different communication partners, settings, interactional situations, and organizations.

### **6.3 General discussion**

A few interesting issues regarding this research project deserve further discussion. First of all, we assumed that it is complex for the hearing and sighted communication partners of a person with congenital deafblindness to focus simultaneously on the content of the person's idiosyncratic expressions and the underlying interactions and emotional exchanges during their conversations. Therefore, IMAI-based interventions are divided in two subsequent phases: communication partners are first trained to foster affective involvement during interaction and next to foster affective involvement during communication. We defined interaction as "the process of mutually influencing each other's behavior" (Janssen et al., 2003, pp. 198) and communication as "a form of interaction in which meaning is transmitted by use of utterances that are perceived and interpreted by the partner" (Janssen et al., 2003, pp. 198). It proved possible to foster affective involvement during both phases, and communication partners confirmed that the stepwise approach to first focusing on interaction and next on communication was effective. Also, all communication partners found it most difficult to foster affective involvement during communication that focused on sharing experiences and meaning. It remains unclear, however, whether it is absolutely necessary to first train communication partners to foster affective involvement during interaction before moving to communication. We did not investigate what would have been the outcome when communication partners would have been trained on fostering affective involvement during communication only. Future studies should further explore the need for a two-phased intervention.

Second, the communication partners indicated that sharing positive emotions was easier than sharing negative ones when fostering affective involvement with the participants with deafblindness. It may be assumed that they were therefore inclined to share more positive emotions than negative emotions. We did not investigate whether this was the case. Time limitations did not allow for more detailed transcriptions of affective involvement. However, gaining more knowledge about how and which emotions are shared with persons with congenital deafblindness could help improve the guidelines for fostering affective involvement. Future studies should shed more light on this.

Third, it was remarkable to discover that negative emotions decreased in all nine participants with congenital deafblindness and that positive emotions increased in eight participants after onset of the intervention on fostering affective involvement. Even though affective involvement could not be fostered in the case of Nick (see chapter 4), his negative emotions decreased. These findings suggest that the IMAI-based interventions are a useful method for preventing challenging behaviors in people with congenital deafblindness when these behaviors are caused by constraints in interaction and communication.

Fourth, coordinated social interactions (which are required for exchanging thoughts and feelings) can only be established if communication partners support the person with congenital deafblindness to become a more interactive communication partner (Nelson, Van Dijk, & McDonnell, 2002). Most people with congenital deafblindness will never be able to achieve symbolic understanding, but can use idiosyncratic expressions of communication (Bruce, 2005). Communication partners therefore need to learn to become meaningful and trustful partners without having access to a shared formal language system. This implies that they need to be competent and inventive in creating dynamic emotional exchanges based on non-symbolic means of communication in various contexts (Hart, 2010; Prain, 2012). Our results showed that very little affective involvement occurred during baseline in the nine single-subject case studies, regardless of the communication partners' work experience and knowledge and skills and the expertise of the different organizations. However, we also found that coaching communication partners with mainly video analysis and video feedback increased affective involvement in eight of the nine cases during both phases of the intervention. Portraying emotional expressions and discussing possible ways of sharing emotions in different contexts appeared to increase the communication partners' skills for fostering affective involvement. Moreover, some communication partners noted that fostering affective involvement increased their feelings of self-confidence with regard to fostering emotion regulation in the person with congenital deafblindness. Follow-up measures, however, showed that in most cases affective involvement decreased after the end of the intervention. This suggests that it is difficult to continue sharing emotions during interaction and communication without support and that communication partners should receive coaching on a regular basis or at regular intervals. Longitudinal studies may indicate whether providing communication partners with more regular coaching would help maintain the increased levels of affective involvement.

Fifth, it may be assumed that the educational background and work experience of communication partners affects their ability to foster affective involvement in people with congenital deafblindness. We found that all communication partners learned to foster affective involvement during the 20-week intervention, but we did not investigate whether the communication partners' ability to foster affective involvement and the extent to which it increased during coaching was related to their level of education

and work experience. Future studies should explore this, because this information is relevant for determining the number of coaching sessions and for reducing the costs of the intervention.

Sixth, the three empirical studies involved seven coaches who applied the IMAI intervention protocol. These coaches were trained to apply the IMAI and were supervised by the researcher (first author) while implementing the intervention. We did not measure whether the coaches optimally trained the communication partners; nor did we examine how the coaches evaluated the applicability and effectiveness of the intervention. As a result, we do not know whether the coaches used the best structure for the coaching sessions and whether this affected the outcomes of the case studies. It is therefore important that future research examines differences between coaches and measures how coaches judged their own performance and the applicability of the intervention. Such knowledge may contribute to further improving the intervention.

Finally, the IMAI was applied to persons with congenital deafblindness who receive services from Dutch organizations. The outcomes of the studies conducted in this research project cannot automatically be generalized to other countries because of possible cultural differences in social contact. It would be interesting to investigate cultural aspects such as how affective involvement can be described and evolves in cultures where physical contact is more common from birth and whether higher levels of physical contact are associated with higher levels of affective involvement between persons with congenital deafblindness and their communication partners.



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